MyPART - My Pediatric and Adult Rare Tumor Network

Natural History Study of Rare Solid Tumors

1. What is a natural history study?
   - An observational study
   - Follows a disease over a long period of time to learn how it changes
   - Not a treatment trial

2. How do you participate?
   - From home:
     - Give us permission to access your medical records and any tumor biopsies
     - Spit into saliva sample collection tube
     - Mail saliva sample to medical center
     - Fill out forms on medical history and lifestyle

3. What happens to your samples?
   - Look at your DNA (from saliva) and DNA from your tumor
   - Identify changes in tumor DNA compared to DNA you were born with
   - Combine with information from survey forms and other rare tumors
   - Use what we learn to develop better treatments for rare tumors